Utah Registry of Autism and Developmental Disabilities

About The Autism Spectrum Disorder Reporting Form

What is the Autism Spectrum Disorder Reporting Form?
This is a form to enroll Utah residents who have an autism spectrum disorder (ASD) into the Utah Registry of Autism and Developmental Disabilities. The Registry is part of a larger project to study how many people are affected by ASDs and/or other developmental disabilities (DDs) in Utah. The project is a shared effort of the Utah Department of Health and the University of Utah School of Medicine's Department of Psychiatry. This project is also part of a national network of selected states organized by the Centers for Disease Control and Prevention. The goal of the national network is to understand more clearly how many people are affected by ASDs and other DDs in the United States. A better understanding of who has these conditions can help researchers in discovering possible causes and treatments.

Who should be included in the Registry?
We want to include anyone – children and adults – in the state of Utah who has been diagnosed with an ASD in the Registry. For an individual to be included, an **Autism Spectrum Disorder Reporting Form** must be completed and returned to the Utah Department of Health. This form is NOT intended to diagnose anyone with an ASD. If you think that someone has an ASD, you need first to have that person diagnosed by a professional.

How will the Registry protect my confidentiality?
Any information sent to the Utah Registry of Autism and Developmental Disabilities will be protected as CONFIDENTIAL under Utah state law.

How will it help me (and/or my child) to be a part of the Registry?
The Registry will collect and share information about the number of people in Utah who have ASDs. Any information that is shared will not include names or other personal information of people in the Registry. Information about the number of people who have ASDs will help educators and health care providers plan for future needs and better understand how many individuals will need therapy. The Registry will work with researchers who are studying possible causes and treatments of ASDs. The larger project will also provide information for health care providers and educators in how to identify persons with ASDs.

Parents and families who are part of the Registry will receive a quarterly newsletter with resources for people with ASDs. [Please note: If you do not wish to receive this newsletter, please check the 'No newsletter' box on the Form.]

How do I send in the form?
Send the form to: Utah Registry of Autism and Developmental Disabilities
Utah Department of Health/Child Development Clinic
PO Box 144643
44 North Medical Drive
Salt Lake City, UT 84114-4643

Or fax the form to: **(801) 584-8579** [Please note: This fax will go to a machine in a secure area.]

What if I have questions about this form or about the URADD project?
Call the URADD Project Coordinator at (801) 584-8547 or (800) 829-8200 for more information. You may also go to our web site: http://health.utah.gov/autism/ Thank you for your interest.

Utah Registry of Autism and Developmental Disabilities

Autism Spectrum Disorder Reporting Form

Please note: All information you send to this registry will be protected under Utah state law as CONFIDENTIAL information unless you give your permission for any of it to be released.

Section 1: Individual refers to the person who has an Autism Spectrum Disorder (ASD).

ASD, as used in this survey, refers to any disorder on the Autism Spectrum, including classic autism, Asperger Syndrome, or Pervasive Developmental Disorder (PDD or PDD-NOS).

Last Name	First Name	M.I.	Nickname (If Any)

Former Name(s), if any (i.e., maiden)	Birth date (mm/dd/yyyy)	Sex ☐ Male ☐ Female	Birth City and State

Current Address - Street	City	State	Zip

Telephone ( ) _____-_____	Last Four (4) Digits of The Individual's Social Security Number (if available)
Email Address	Ancestry or Ethnic Origin (write in) – For example, Hispanic, Asian, etc.

Name of Person Completing this Form	Relationship of this Person to the Individual with ASD ☐ Biological Mother ☐ Biological Father ☐ Adoptive Parent ☐ Legal Guardian ☐ Stepparent ☐ Individual with ASD ☐ Other (Specify)
Is your address the same as the individual's (above)? ☐ Yes ☐ No If 'No', please write your address below:	

Street	City	State	Zip

Daytime Phone ( ) _____-_____	Evening Phone ( ) _____-_____	Cellular or Other Phone Number ( ) _____-_____

Parent Information Information on the individual's biological parents is not available ☐

Does the individual currently live with the biological mother? ☐ Yes ☐ No
Does the individual currently live with the biological father? ☐ Yes ☐ No

In what one location did the biological mother live for <u>most</u> of the first three months of her pregnancy? ☐ I don't know

Street	City	State	Zip

In what one location did the individual live for <u>most</u> of his/her first year of life? ☐ I don't know

Street	City	State	Zip

List any drugs or medicines (over the counter or prescription) that the biological mother took during her pregnancy (if known)

Did the biological mother have any miscarriages or stillbirths? ☐ Yes ☐ No ☐ I don't know

If 'Yes', how many miscarriages or stillbirths did she have? ☐ I don't know how many

Name of biological mother (if available). Please give current name first and include former names (i.e., maiden, other married)
Has the biological mother been diagnosed with an autism spectrum disorder? ☐ Yes ☐ No ☐ I don't know
Name of biological father (if available). Please give current name first and include any former names
Has the biological father been diagnosed with an autism spectrum disorder? ☐ Yes ☐ No ☐ I don't know

	Biological Mother	Adoptive Mother or Legal Guardian (if different)	Biological Father	Adoptive Father or Legal Guardian (if different)
Ancestry or Ethnic Origin (write in)				
Occupation (write in)				

Sibling Information **The individual has no siblings, half-siblings, adopted or step siblings ☐**

Sibling's name or initials	Sex	Kinship	Month/year of birth	Has this sibling been diagnosed with an autism spectrum disorder?	Does this sibling have <u>any</u> other disability?
1.	☐ Male ☐ Female	☐ Whole (both parents are the same) ☐ Half (one parent is the same) ☐ Adopted or step (different biological parents)	_____/_____	☐ Yes ☐ No ☐ I don't know	☐ Yes ☐ No ☐ I don't know
2.	☐ Male ☐ Female	☐ Whole ☐ Half ☐ Adopted or step	_____/_____	☐ Yes ☐ No ☐ I don't know	☐ Yes ☐ No ☐ I don't know
3.	☐ Male ☐ Female	☐ Whole ☐ Half ☐ Adopted or step	_____/_____	☐ Yes ☐ No ☐ I don't know	☐ Yes ☐ No ☐ I don't know
4.	☐ Male ☐ Female	☐ Whole ☐ Half ☐ Adopted or step	_____/_____	☐ Yes ☐ No ☐ I don't know	☐ Yes ☐ No ☐ I don't know
5.*	☐ Male ☐ Female	☐ Whole ☐ Half ☐ Adopted or step	_____/_____	☐ Yes ☐ No ☐ I don't know	☐ Yes ☐ No ☐ I don't know

***If the individual has additional siblings, please provide information on those siblings on the reverse side of this page.**

Other Family Information

Have any of the individual's parents or siblings been diagnosed with depression, bipolar disorder or a mood disorder? ☐ Yes ☐ No ☐ I don't know
Have any of the individual's cousins, uncles or aunts been diagnosed with an autism spectrum disorder? ☐ Yes ☐ No ☐ I don't know

Section 2: Diagnostic Information

What ASD diagnosis has the individual received? (Check all that apply)

□ Autism or Autistic Disorder
□ Asperger Syndrome
□ Pervasive Developmental Disorder (PDD or PDD-NOS)
□ Rett Syndrome
□ Childhood Disintegrative Disorder (CDD)
□ Has 'autistic tendencies or symptoms'
□ Other (please specify): _____

Who diagnosed the individual as having autism?

Name: _____ Facility or Clinic: _____

City, State: _____

Who is the individual's **current** primary care provider?

Name: _____ Facility or Clinic: _____

City, State: _____

How old was the individual when this diagnosis was first made?

Age: _____ months _____ years old

How old was the individual when their parents/guardians first suspected that the individual might not be developing like other children?

Age: _____ months _____ years old

What were the initial concerns? (Check all that apply)

□ Delayed language
□ Didn't respond to name
□ Didn't enjoy being cuddled or touched
□ Impaired social skills
□ "In his/her own world"
□ Insistence on "sameness"
□ Intense focus on single or few subject(s)
□ Limited eye contact
□ Loss of language skills
□ Repetitive behaviors
□ Suspected hearing loss
□ Tantrums or "meltdowns"
□ Other (please specify): _____

Does the individual currently have any of the following? (Check all that apply)

□ Purposefully does things that injure or hurt himself/herself
□ Has frequent difficulties with constipation and/or diarrhea
□ Is not able to consistently sleep through the night
□ Is overly or less active compared to others of the same age

Has the individual been diagnosed with other medical conditions, birth defects, developmental delays, or disabilities?

□ Yes □ No If 'Yes', please list:

If the individual has been diagnosed with seizures or epilepsy, who made this diagnosis?

Name: _____ Facility or Clinic: _____

City, State: _____

Has the individual been classified or diagnosed as being mentally retarded or intellectually disabled (I.Q. score below 70)?

□ Yes □ No □ I don't know

How old was the individual when the most recent I.Q. test was given to them? Age: _____ months _____ years old

□ I don't know □ No I.Q. test was ever given to this individual

Section 3: School/Employment Information

For individuals from birth to 18 years of age

Early Intervention is a publicly funded program for children 0-3 years of age who have developmental delays or disabilities. If the individual did (or does currently) receive services from an Early Intervention program, please indicate where these services were (or are) received:

School or Program	City	State

What type of school does the individual attend? (Check the school setting that best describes the individual's school situation)

□ Autism preschool program □ Special ed preschool □ Regular ed preschool
□ Public school with special ed services □ Public school with resource room services
□ Public school with no resources □ Autism school program □ Private school
□ Home-schooled □ Too young to attend school □ Institutional care setting
□ Not in school □ Other (please specify):_____

If the individual attends a public or private school, please give the name and setting of the school:

Name of the school	School district	City	County

An IEP or (Individualized Education Program) is a detailed description of a child's educational program that is used in a public school setting. Children who have an IEP receive at least some special education services. Does the individual have an IEP (Individualized Education Program) at their school?

□ Yes □ No □ I don't know

For only those individuals who are receiving special education services at school: What are the reasons that the school has given you to explain why the individual receives these services? (Check all that apply)

□ Autism □ Communication disorder (speech/language impairment)
□ Deaf/blindness □ Developmental delay (for children under 7 only)
□ Emotional disturbance □ Hearing impairment/deafness
□ Intellectual disability □ Multiple disabilities
□ Orthopedic impairment □ Specific learning disabilities
□ Traumatic brain injury □ Visual impairment
□ Other health impairment □ The individual does not receive special education services
□ I don't know

For individuals 18 years of age or older

What does the individual do? (Check all that apply)

□ Is employed full time, with no supports
□ Is employed full time, with supports
□ Is employed part time, with no supports
□ Is employed part time, with supports
□ Other (please specify): _____

□ Is not employed
□ Attends College/University/other higher education
□ Is in public school transitional services (for adults 18-21 only)
□ Works in a sheltered workshop or does volunteer work
□ I don't know

How or where does the individual live?

□ Independently, with no assistance
□ Independently, but with some assistance
□ In a group home
□ Other (please specify): _____

□ With parent(s), guardian(s), or sibling(s)
□ In an institutional care setting
□ In a higher education dormitory
□ I don't know

Please sign and date this form before sending it in. Thank you.

_____ _____
Signature Date

Please check the 'Yes' or 'No' box below to let us know if you would like to receive the Utah Department of Health's quarterly newsletter. This newsletter will contain information about autism spectrum disorders.

□ Yes, I would like to receive UDOH's newsletter by (please select one):

□ Email - Preferred email address: _____

□ Regular mail

□ No, I would not like to receive UDOH's newsletter.